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1. Culture-Bound Syndromes and the Dhat Syndrome

2. Applied Cognitive Psychology: Attentional Mistakes

3. The Social Networks of Adults with Learning Disabilities: The Importance of Opportunities

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Culture Bound Syndromes and the Dhat Syndrome

INTRODUCTION

Yap (1962) first proposed the idea of disorders specific to particular cultures under the term "atypical cultural bound psychogenic psychosis". This, thankfully, became the more "acceptable", "culture bound syndromes" (Yap 1969) (1).

Littlewood and Lipsedge (1985) defined culture bound syndromes (CBS) as "episodic and dramatic reactions specific to a particular community - locally defined as discrete patterns of behaviour".

In the ninth appendix of DSM-IV, CBS are defined as "recurrent, locality-specific patterns of aberrant behaviour and troubling experience that may or may not be linked to a particular DSM-IV diagnostic category" (APA 1994 p844).

From a critical stance, Hughes (1996) argued that CBS only afflict the "other" (ie: outsiders). These outsiders could be within the society or culture itself, or, at a global level, those outside of Western psychiatry. This is particularly the case when terms like "exotic syndrome" or "folk illness" have been used (Sumathipala et al 2004a).

It is interesting that certain disorders that predominate in the West (eg: type A personality - Hughes 1996; bulimia nervosa - Littlewood 1996) (2) are not seen as CBS by psychiatrists, but are "true" (or universal) disorders yet to be discovered elsewhere or labelled correctly. But all disorders (or "psychiatric patterns") are culture-bound (Littlewood 1996).

It is important that Western ethnocentric attitudes do not mean that CBS are treated as "second-class status differentiating it from 'professional illness'" (Simons 1987). The classification systems used by psychiatrists, ICD-10 (WHO 1992) and DSM-IV (APA 1994), have attempted to take a "theoretically neutral position" by incorporating "culture as a factor in the diagnosis of psychiatric conditions" (Sumathipala et al 2004a).

CLASSIFICATION OF CULTURE BOUND SYNDROMES

Berry et al (1992) made the distinction between disorders that are:

i) Absolute - the same in all cultures;

ii) Universal - found in all cultures but have local variations (3);

iii) Culturally relative - found in certain cultures only.

CBS would be seen as category (iii). But not all CBS are viewed the same. McCajor Hall (1998 quoted in Humphreys 1999) listed thirty-six different examples of CBS divided into six types. These types can be described as:

1. A disorder that occurs in one culture, but it is not recognised in the West - eg: amok (South East Asia): brief, wild, aggressive behaviour after a period of brooding, usually by men (4); hsieh-ping (Taiwan): the individual is briefly possessed by an ancestral ghost.

2. A disorder that occurs in one culture, and is similar (in part) to categories in DSM-IV ands ICD-10 - eg: taijin kyofusho (Japan): the fear that the body and its functions are embarassing or offensive to others (similar to social phobia); susto (Latin America): unhappiness and illness caused because the soul has left the body after a frightening event (similar to major depression disorder; Brewer 2001; or post-traumatic stress disorder).

3. A disorder that is not yet recognised in the West - eg: kuru (New Guinea): a form of dementia associated with cannibalism.

4. A behaviour found in many cultures, but only seen as a disorder in some - eg: koro (China): the fear that the penis is retracting into the body and this could lead to death; zar (North Africa): possession by a spirit that causes the individual to laugh, shout or sing.

5. Explanations of illness used by many cultures, but viewed as wrong by Western psychiatrists - eg: evil eye (Middle East); rootwork (southern USA): an explanation for illness based on witchcraft or voodoo.

6. A disorder occurring in some cultures which does not exist - eg: windigo (Algonkian Indians): feelings of depression and anxiety leading to possession by a giant man-eating monster which causes cannibalism.

Figure 1 shows these categories in relation to

Western psychiatry. Using the above categories, dhat syndrome would be classed as category two.

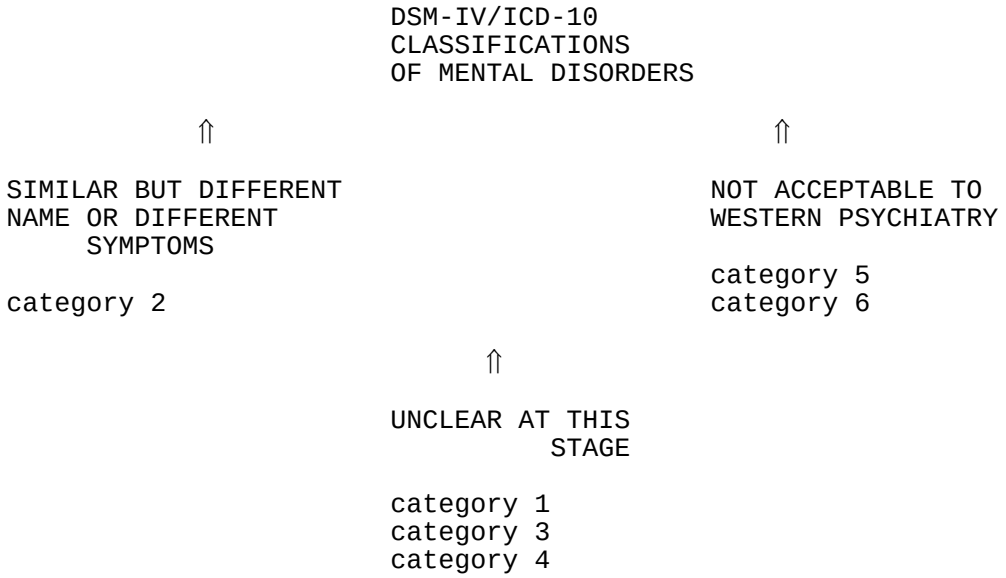

Figure 1 - McCajor Hall's categories of CBS and Western psychiatry.

DHAT SYNDROME

Dhat syndrome can simply be called "semen loss anxiety", and not surprisingly, only afflicts men (5)(6).

Sumathipala et al (2004a) felt that:

> The loss of semen is wrapped up in men's perception of their masculinity, thus the hypochondriacal, anxiety and depressive symptoms become subsumed in the major visible "pathology" of semen loss (p210).

Dhat syndrome was first described in Western psychiatry by Wig (1960), though it has been known about for much longer in, for example, India. In fact, dhat comes from a Sanskrit word (dhatu). The symptoms include fatigue, anxiety, loss of appetite, guilt, and sexual dysfunction attributed to loss of semen in nocturnal emissions, masturbation or in urine (Samathipala et al 2004a) (6).

Historically, and around the world, many writers have been concerned about the negative consequences of semen loss. Texts from India, as early as 1500 BC, talked of the preservation of semen as a guarantee of good health. Galen, a second century Greek, wrote that "losing sperm amounts to losing the vital spirits". More recently, Sigmund Freud, writing in the early twentieth

century, linked anxiety problems (neurasthenia) to masturbation in puberty (Sumathipala et al 2004a). Today, dhat syndrome is most common in Asia, in particular India and Sri Lanka.

Malhorta and Wig (1975) questioned a random sample of 175 middle-aged men in an Indian city. The majority saw semen loss as harmful. But there were differences in beliefs about its cause based on social class.

While men at a clinic for sexual dysfunction in Sri Lanka tended to see excessive semen loss as the cause of their sexual problems (De Silva and Dissanayake 1989).

In terms of the prevalence rate, Bhatia and Malik (1991) recorded 42% of patients at an Indian clinic for sexual dysfunction as having "pure" dhat syndrome.

Sumathipala et al (2004a) argued that dhat syndrome is a cultural manifestation of universal symptoms of anxiety (8). Historically (eg 19th century), in the West, there was great concern about semen loss:

> Our contention is that with industrialisation and urbanisation, the anxiety about semen loss in the West diminished, and the same is likely to happen in South Asia as well (p207).

So, for them, dhat syndrome is not a CBS, but a manifestation of anxiety and depression only diagnosed as dhat syndrome in certain countries today (9). What is common between periods in the West when semen loss anxiety existed and modern day India is a "hostility to sex" (Sumathipala et al 2004a). The male pre-occupation with semen loss is and has been universal.

Sumathipala et al (2004b) were concerned that calling a disorder, like dhat syndrome, a CBS dismisses it in some way:

> We believe that culture-bound syndrome as a nosological category is a colonial intervention and deserves to be dumped in the bin of history. We agree that culture plays a key role in how symptoms are allowed and encouraged to be developed and expressed by individuals. However, the role of culture is essential for all our patients and not a few selected ones. Everyone is culture (p262).

FOOTNOTES

1. Shankar and Gilligan (2004) preferred to use the term "culture-related specific syndrome".

2. Other disorders in DSM-IV proposed as possible Western CBS include agoraphobia (Dein 1997), dissociative identity disorder (Merskey 2000), and chronic fatigue syndrome (Sharpe and Wessely 2000).

For Kleinman and Cohen (1997), it is an unhelpful myth that unusual cultural-specific disorders only occur outside the West, and means that psychiatrists are missing problems.

3. For example, delusions and hallucinations in schizophrenia vary between cultures - in the West, they relate to technology (eg: being controlled by a computer), while in Africa, they are more related to religion (eg: being controlled by a spirit) (Dein 1997).

4. Sumathipala et al (2004b) asked the question "why amok in Malaysia is seen as a culture-bound syndrome but similar behaviour of random shootings and running 'amok' is not seen in this way in the USA?".

5. Also called "jiryan" in Pakistan (Dein 1997), and similar to "shen-k'uei" in Chinese medicine (Sumathipala et al 2004a).

6. A debated version called "pure" dhat syndrome tends not to have hypochondriacal preoccupations (ie other health concerns) (Chadha and Ahuja 1990).

7. There are female equivalents, in South Asia, concerned with the loss of genital secretions (leucorrhoea; Karen 2001).

8. Other examples of cultural differences include the emphasis on physical symptoms (somatization) (eg: aching joints) as presentations of depression in Asia (Dein 1997). There are various "idioms of distress" (Bhugra and Mastrogianni 2004) (table 1).

CULTURE	IDIOMS OF DISTRESS
India	sinking heart, feeling hot, gas
Nigeria	heat in head, biting sensation all over body, heaviness sensation in head
Mexican Americans	"nervios" eg brain ache or brain exploding

Table 1 - Three examples of somatic "idioms of distress".

9. Mumford (1996), after studying men in India, felt that semen loss anxiety was a cultural manifestation of the

universal underlying disorder of depression.

REFERENCES

APA (1994) Diagnostic and Statistical Manual of Mental Disorders (4th ed) (DSM-IV), Washington DC: American Psychiatric Association

Berry, J.W et al (1992) Cross-Cultural Psychology, Cambridge: Cambridge University Press

Bhatia, M.S & Malik, S.C (1991) Dhat syndrome. A useful diagnostic entity in Indian culture, British Journal of Psychiatry, 159, 691-695

Bhugra, D & Mastrogianni, A (2004) Globalisation and mental disorders, British Journal of Psychiatry, 184, 10-20

Brewer, K (2001) Clinical Psychology, Oxford: Heinemann

Chadha, C & Ahuja, N (1990) Dhat syndrome. A sexual neurosis of the Indian subcontinent, British Journal of Psychiatry, 156, 577-579

Dein, S (1997) ABC of mental health: Mental health in a multiethnic society, British Medical Journal, 23/8, 473-476

De Silva, P & Dissanayake, S.A.W (1989) The loss of semen syndrome in Sri Lanka. A clinical study, Sexual and Marital Therapy, 4, 195-204

Hughes, C.C (1996) The culture bound syndromes. In Mezzich, J et al (eds) Culture and Psychiatric Diagnosis: A DSM-IV Perspective, Washington DC: American Psychiatric Association

Humphreys, P (1999) Culture bound syndromes, Psychology Review, November, 14-18

Karen, T-K (2001) Cultural and biomedical meanings of the complaint of leukorrhea in South Asian women, Tropical Medicine and International Health, 6, 260-266

Kleinman, A & Cohen, A (1997) Psychiatry's global challenge, Scientific American, March, 74-77

Littlewood, R (1996) Cultural comments on culture bound syndromes: I. In Mezzich, J et al (eds) Culture and Psychiatric Diagnosis: A DSM-IV Perspective, Washington DC: American Psychiatric Association

Littlewood, R & Lipsedge, M (1985) Culture bound syndromes. In Granville-Grossman, K (ed) Recent Advances in Clinical Psychiatry, Edinburgh: Churchill Livingstone

Malhorta, H.K & Wig, N.N (1975) A culture bound sex neurosis in the Orient, Archives of Sexual Behaviour, 4, 519-528

Merskey, H (2000) Conversion and dissociation. In Gelder, M.G; Lopez-Ibor, J.J & Andreasen, N (eds) New Oxford Textbook of Psychiatry vol 2, Oxford: Oxford University Press

Mumford, D.B (1996) The "Dhat syndrome": A culturally determined symptom of depression? Acta Psychiatrica Scandinavica, 94, 3, 163-167

Shankar, B.R & Gilligan, D (2004) Correspondence, British Journal of Psychiatry, 185, 261

Sharpe, M & Wessely, S (2000) Chronic fatigue syndrome. In Gelder, M.G; Lopez-Ibor, J.J & Andreasen, N (eds) New Oxford Textbook of Psychiatry vol 2, Oxford: Oxford University Press

Simons, R.C (1987) Commentary on Prince and Tchang-Laroche "Culture bound syndromes and international disease classifications", Culture, Medicine and Psychiatry, 11, 21-28

Sumathipala, A; Siribaddana, S.H & Bhugra, D (2004a) Culture bound syndromes: The story of dhat syndrome, British Journal of Psychiatry, 184, 200-209

Sumathipala, A; Siribaddana, S.H & Bhugra, D (2004b) Author's reply, British Journal of Psychiatry, 185, 261-262

WHO (1992) International Statistically Classification of Diseases and Related Health Problems (ICD-10), Geneva: World Health Organisation

Wig, N.N (1960) Problems of the mental health in India, Journal of Clinical and Social Psychiatry, 17, 48-53

Yap, P.M (1962) Words and things in comparative psychiatry with special reference to exotic psychosis, Acta Psychiatrica Scandinavica, 38, 157-182

Yap, P.M (1969) Koro: A culture bound depersonalisation syndrome, British Journal of Psychiatry, 111, 43-45

Kevin Brewer

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Applied Cognitive Psychology: Attentional Mistakes

INTRODUCTION

The senses are bombarded with many stimuli from the outside world, including sights and sounds, as well as what is going on inside the body (eg: hunger or train of thoughts). The brain cannot cope with all this input, so there is a need to be selective about what attention is paid to.

William James (1890) defined attention as "the taking possession by the mind in clear and vivid form of one out of what seems several stimulus objects or trains of thought". Thus attention is the ability to concentrate upon what is important in the environment, and ignore what is not important.

Where individuals are involved in familiar tasks (like driving a car), parts of the process become automatic. This applies to the attention involved in driving, for example, on a quiet motorway.

It is not that the individual is not paying attention to the road, it is that they are paying little conscious (or focal) attention. The task is allocated little resources from the attentional capacity (Kahneman 1973). While driving in busy situations requires a lot of focal attention.

The upshot of paying little attention when driving are accidents, and, in particular, "looked but failed to see" accidents.

"LOOKED BUT FAILED TO SEE" ROAD TRAFFIC ACCIDENTS

"Looked but failed to see" (LBFS) (1) are a class of road traffic accident where drivers hit something which they later claim they did not see.

This type of accident is more common at road junctions, and often involves cyclists or motorcyclists as the victims (Edgar 2002). It is a failure of visual search (2).

One explanation is that there is a failure to detect a relatively small target (eg: cyclist) because it is not bright enough, for example.

This relates to "sensory conspicuity" - "the likelihood that an object will be detected based on its intrinsic properties registered by the senses, such as shape, colour, brightness" (Edgar 2002 p38). So the

answer would be to make cyclists easier to see with brighter clothes, for example.

But Cole and Hughes (1984) argued that the cause may be "attention conspicuity". This is "the likelihood that an object will draw attention to itself" (Edgar 2002 p38), and factors like expectation and previous knowledge play a role. So if a driver is not expecting to see a cyclist, they will not perceive one however visible the cyclist tries to be. In other words, cyclists in bright clothes also get hit in LBFS road accidents. Things with high sensory conspicuity get hit because they are not expected.

Research has shown this to be the case in situations where stationary police cars blocking off a lane on a road get hit. Police cars are fitted with "sensory conspicuity enhancers" (eg: flashing lights, reflective material), yet they are still hit by drivers as LBFS accidents. This is a failure of vigilance (3).

Work by Martin Langham (1999 quoted in Edgar 2002) (4) has studied this problem. Information was sort from police forces about LBFS accidents involving police cars being hit while blocking off a lane on a road.

Details of twenty-nine vehicle accidents were defined as useable under the following criteria:

- The police vehicle had "sensory conspicuity enhancers";
- An actual collision took place;
- The driver claimed afterwards that they did not see the police vehicle in time to stop;
- Not a deliberate attempt to hit the police vehicle.

As many details as possible were obtained about each accident (eg: weather, viewing conditions).

A number of key patterns emerged from analysis of the twenty-nine accidents:

i) More police vehicles were hit when parked "in line" (facing the same direction as the traffic flow) than when parked "echelon" (parked side-on across the lane);

ii) The use of warning signs and cones did not guarantee that drivers would detect the parked police cars;

iii) Many of the accidents occurred close to the perpetrator's home where they knew the roads;

iv) Most of the drivers were over twenty-five years old and were experienced at driving.

These findings fit with LBFS accidents being due to attention conspicuity. Driving a car for an experienced driver involves tasks that the individual is familiar with, and thus is done automatically. Conscious attention may be focused on something else.

In situations like this, expectations and previous knowledge are key. It is not expected that cars will be parked in a lane of the road, especially on a motorway. Cars parked echelon are unexpected and this produces a conscious attentional response.

The more experienced the driver, the more likely they will be driving automatically and depending more on expectations and previous knowledge. Less experienced drivers will be paying more conscious attention, and if they hit a stationary vehicle, the way it is parked will not matter.

Langham et al (1998 quoted in Edgar 2002) (5) set up an experiment to test this difference. Experienced or inexperienced drivers were shown video clips (filmed from a moving car) and asked to identify driving hazards as quickly as possible. One set of video clips involved a stationary police car parked either in-line or echelon. Experienced drivers had a faster reaction time for recognising the echelon-parked car than the in-line one, while inexperienced drivers showed no difference.

Overall, attention in driving is based partly on actual awareness of the road, and partly on past knowledge and expectations. This can also be seen with "change blindness" or "inattentional blindness".

NOT SEEING THE OBVIOUS

"Change blindness" is where individuals will not notice obvious changes in the environment if the changes are not felt to be important (ie: not attended to).

Simons and Levin (1998) set up a field experiment on a US university campus where a stranger would change appearance halfway through a conversation. The aim was to see if the participants noticed.

For example, at a reception desk, the attendant reaches behind a door and another person takes their place. It may seem obvious that we will notice it is a different person, but half the participants did not.

It is not necessary to attend to the actual details of the person in such a situation, and so that information is not selected. At a reception desk, the

information attended to relates to the instructions given not the person giving them, unless the information about the person there is important.

With "inattentional blindness", individuals do not pay attention to something that seems unimportant.

Simons and Chabris (1998) asked participants to watch a seventy-five second video clip of a basketball match played in the street and count the number of passes by one team.

During the video clip, a person in a gorilla suit or a woman carrying an umbrella walk across the middle of the court (an event lasting five seconds). About 30% of the participants did not notice this event because it was not perceived as important to the task at hand (counting the number of passes).

In another video clip of the same match (lasting sixty-two seconds), the person in a gorilla suit stops in front of the camera for nine seconds. Six out of twelve participants failed to notice this event.

This research on "the phenomena of change blindness and inattentional blindness suggest that we may not be as consciously aware of the details of our normal visual environment as we generally feel we are" (Datta 2004 p179).

FOOTNOTES

1. The term, "looked but failed to see" accidents, first coined in Sabey, S & Staughton, G.C (1975) Interacting roles of road environment, vehicle and road user, 5th International Conference of the International Association for Accident Traffic Medicine, London; Crowthorne, Berks: TRLL

2. Visual search is the process of picking out a particular target within distractor items. In lab experiments, participants are asked to find the letter "T", for example, among numbers of "C" and "S" (Brewer and Reinicke 2004).

3. Vigilance involves watching for the appearance of a target over a period of time.

In lab experiments, participants watch a screen and report when a particular target appears (like on a radar screen).

4. Langham, M.P (1999) An Investigation of the Role of Vehicle Conspicuity in the "Looked but Failed to See" Error in Driving, unpublished PhD, University of Sussex.

5. Langham, M.P; Hole, G; Edwards, J & O'Neil, C (1998)

Can the "looked but failed to see" error involve highly conspicuous police patrol cars? Evidence from accident reports and lab studies, 1st Engineering Psychology Conference, BPS Special Interest Group, University of Southampton.

REFERENCES

Brewer, K & Reinicke, H (2004) The Psychology of Attention: Methodology and Brief Introduction, Orsett, Essex: Orsett Psychological Services

Cole, B.L & Hughes, P.K (1984) A field trial of attention and search conspicuity, Human Factors, 26, 3, 299-313

Datta, S (2004) Understanding the mind. In SD226 Course Team (eds) From Cells to Consciousness, Milton Keynes: Open University

Edgar, G (2002) Perception and attention. In Miell, D; Phoenix, A & Thomas, K (eds) Mapping Psychology 2, Milton Keynes: Open University

James, W (1890) The Principles of Psychology, New York: H.Holt & Co

Kahneman, D (1973) Attention and Effort, Englewood Cliffs, NJ: Prentice Hall

Simons, D.J & Chabris, C.F (1998) Gorillas in our midst: Sustained inattentional blindness for dynamic events, Perception, 28, 1059-1074

Simons, D.J & Levin, D.T (1998) Change blindness, Trends in Cognitive Science, 1, 7, 261-267

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The Social Networks of Adults With Learning Disabilities: The Importance of Opportunities

INTRODUCTION

Within the literature regarding adults with learning disabilities (AWLD), physical disabilities, mental ill health, the elderly, comparative and normative studies, social networks are defined in a plethora of ways. Classically, the quantitative structural components of networks have been the focus, defined as "a web of relationships attached to an individual" (Barnes 1954).

Components include the size (or number of persons), membership categorised under headings (eg family, staff), density (ratio of people known to one another), and frequency of interaction - a quantitative account.

Size was recognised by network analysts as potentially limitless (Hammer 1980), and focused upon the "support network" as a functional aspect. This became the dominant unit of study in the UK, but was deemed too narrow (Pahl and Quine 1985) as the studies demonstrated that comparatively few people play supportive roles.

Emerging and apparent within the literature is that functions of entire networks and the typologies of social support are wide and differ comparatively between AWLD and ordinary citizens. The typical four functions of networks, or types of support, within the literature are physical, emotional, company, and information.

The typology is very much dependent upon the group, but the broad evidenced typologies for normal populations such are, for example, emotional, problem-solving, indirect personal influence and environmental action, and material, behavioural, intimate interaction, guidance, feedback, and positive social interaction (Gottlieb 1978).

These differentially compare unfavourably with the seven typologies emergent in specific and specialist literature for AWLD. These more specific typologies are personal (washing and bathing), household, material, decision-making and feedback, confiding, company and invisible support (Forrester-Jones 2002b).

This leads to the working definition of current research on social networks as "an opportunity structure, which may or may not provide social support" (Forrester-Jones and Grant 1997).

THE CONTEXT OF SOCIAL NETWORK RESEARCH

Specialist literature has attempted to address the issue that AWLD still experience a life of "isolation and

disengagement" (Rapley and Beyer 1996). AWLD often have limited social networks in terms of size and density in comparison to normal populations (eg: Emerson et al 2001).

Overall network size is small and dense, estimated at twenty-two in the "Twelve Years On" study (DoH 1989; Forrester-Jones et al 2001), and is further reduced for those with dual-diagnosis (learning disability and mental health problems).

Normal population research (eg: Milardo 1992) suggested that up to five significant others (family and friends) combined with twenty people to provide material and emotional assistance (Fisher 1982) plus twenty to one hundred in interactive, frequent contact, and unlimited global networks make up an entire network.

The social networks of AWLD are also known to be limited in their composition, comprising often of family and paid staff (McConkey and McGinley 1990; Newton et al 1995), as compared to normal populations that include wider membership categories and less density.

However, the universal importance of social networks have been systematised to life. Health (eg: Blaxter 1990, Benzeval et al 1995), stress reduction and psychological well-being, successful community living, self-esteem (Smith and McCarthy 1996), friendship, and even reduced mortality (Brown and Harris 1978) are all benefits of social networks. But dangers and risks include verbal and physical abuse (eg: Cambridge et al 2002), and these must be carefully managed (Forrester-Jones et al 2001).

Apparent within specialist and comparative literature is the influence and impact of mediating factors that influence social contact and forming of relationships (Srivastava 2001). These include social and political circumstances, such as living arrangements, service systems, and access to services, ideological value-based agendas such as "normalisation" policy, their own self-concept and/or skill level, the impact of ageing, and the degree of learning disability with regard to skills and behaviour.

These mediators have been grouped into three areas that effect the formation of relationships (Srivastava 2001):

a) Community barriers including deinstitutionsalisation of both hospitals and day centres;

b) Social factors including relationships between AWLD and others (including staff), and management/staff philosophy (Forrester-Jones and Grant 1997);

c) Individual factors such as skill level, behavioural problems, and aspects of choice and reciprocity.

OPPORTUNITY: "IN, NOT OF THE COMMUNITY" (Myers et al 1998)

Living Arrangements

The living circumstances of AWLD and the impact of this status upon social networks are apparent within the literature. Embedded within the deinstitutionalisation agenda of the 1960s and 1970s was a unanimous rejection of segregation. There can be no doubt that social networks form a key aspect of community inclusion, the other being use of community resources (Szivos 1992).

However, "the danger lies in confusing the two meanings (geography and friendship network) in a glow of nostalgia and fantasy so that the geographical location is expected to yield friendship networks" (Szivos 1992). Being integrated into "the community" clearly does not amount to being "included" and this danger has clearly been realised.

Friendship development (as a benefit of social networks) is often considered the least successful aspect of community-based care (Booth et al 1990), as opposed to institutions. But it is often the lynch pin around which the success of a community placement pivots (Holland and Meddis 1997). It is clear that it was hoped that the closure of long stay hospitals and moves to the community would result in greater opportunity for friendships. However, the majority of evidence would suggest that, following a move from the institution to a community setting, social networks remained limited to relatives, other service users and staff (eg: de Kock et al 1998) with substantial proportions of people having no identifiable friends outside these groups (Rapley and Beyer 1996).

Within a limited network, staff characteristics, the ambiguity of their roles, number of paid staff and the quality of their relationships with AWLD have a huge and wide reaching impact upon social network size and structure. Following deinstitutionalisation and a time of changing paradigms of support, "many staff now find themselves (in the absence of clear direction - or even sometimes with it) cast into the multiple conflicting roles of friend, enabler, advocate, teacher, jailor, home-maker, carer, and therapist" (Emerson et al 2001).

The conflicting expectation of these amorphous roles often serves to paralyse effective action and may set occasion for (possibly unhelpful) personal beliefs to

shape actual performance. This conflict has been described within the literature as a "double bind of support and control" that becomes more irresolvable when the expectation is to be "friend" (Szivos 1992).

In terms of personal beliefs and role ambiguity, David Brandon (quoted in Forrester-Jones 2002a) looked specifically at relationships between staff and residents, and outlined six "dominant but flawed" social interactions: authoritarian, over-protectionism, detachment, surrogate family, paid friendship, and staff as servant.

These interaction mechanisms have clear knock-on effects in terms of opportunities for social interaction. The "Twelve Years On" study (Forrester-Jones et al 2001) highlighted "the need to build constructively on the relationship between staff and service users in new and creative ways, without generating professional or practise compromises".

Effective staff action that has beneficial impact upon social networks includes promoting access to situations where social interaction can occur (Newton et al 1995) and actively using social guidance techniques in the role of teacher. Community residences vary greatly in quality, including that of staff and this lottery really does play a mediating role in social networks.

A further-reaching paradigm that has potentially beneficial outcomes for social networks is supported living (Kinsella 1992), where person-centred planning results in a home of someone's choice, with people of their choice and separately purchased housing and care services. The primacy of natural supports and friendships within the community are paramount. But Emerson et al (2001) highlighted two negative aspects of supported living - the risk of vandalisation, and the higher risk of exploitation.

While those AWLD living in family homes are protected by a culture of family embeddedness (Krauss and Erickson 1998) and it can be argued that this has an impact upon opportunity for social contacts and the building of social networks. Family carers can also be party to the same flawed social interactions as staff members.

Change of networks was also stressful in this context, often brought about by death or illness of parents. However, social support and closeness to family, including siblings were benefits (Grant 1993).

Day Provision

AWLD often access day provision, regardless of their residential status. Pressure on day services to "deinstitutionalise" and support people within the community has been discussed by leading commentators since the 1970s and throughout the 1980s and the 1990s (eg: Kings Fund 1980; 1984; Wertheimer 1996).

Social networks for people without disabilities are not bound by territory and tend to be formed haphazardly, often at work or via leisure pursuits (Szivos 1991). Any increase in frequency of activity can be seen as beneficial to social contact and resulting networks for AWLD (Oulette et al 1994). Leisure as a major social conduit to forming friendships is emergent within the literature.

But segregation in leisure still exists (Wall 1998) and AWLD often engage in solitary leisure pursuits (McConkey and McGinley 1990). Service system constraints such as transport and staffing (Forrester-Jones 2001) and family constraints, such as ageing parents and limited support from professionals, impact upon opportunity to access leisure. Leisure cannot be a mainstay of a person's life (Forrester-Jones 2001).

Although day centres are valued by AWLD and carers for social contact, they are often seen as an alternative to paid work (Simons and Watson 1999). However, the Supported Employment Model (Melling 1997) does seem to offer beneficial outcomes for social networks compared to day centres (Bass and Drewett 1997) and further education.

Beyer's (1996) major study of agencies found that 40% of workers had excellent levels of integration and 38% good levels. Increased disposable income can offer more opportunities for inclusion in the wider community (Simons and Watson 1999).

However, American studies have noted that integration outcomes were not always as advantageous for adults with severe learning disabilities, when compared to those with mild or moderate learning disabilities (eg: Mank et al 1997).

THE INDIVIDUAL EXPERIENCE: POSITIVE AND NEGATIVE

Friendship research has shown that friendship choice, reciprocity and stigma to be unrelated to intellectual functioning, independence in the home, social skills (Smith and McCarthy 1996; Newton et al 1995) with similar findings in mental health research. Friendships are problematic to define as it describes the quality of the relationship, as opposed to social

position such as "neighbour" or "relative" (Fehr 1996).

Also there is the assumption that friends from within a social network from the community are laden with more value than friendships and interaction with fellow disabled people.

However, research and literature reports a sense of "shared history", the importance of friendships with other AWLD (Atkinson 1989).

The psychological process of stigmatisation is also apparent within this "shared history" where hospitals developed hierarchies which have transferred and become part of some people's community experience. It is clearly not beneficial in terms of making relationships. Those that experience the most stigma experience the least self-esteem (Szivos-Bach 1993).

However, studies have shown that acceptance by the community and increased contact (eg: publicans and shopkeepers) were apparent, and that stereotypical views were changing.

Another aspect of stigma is "downward comparison", or stigma by association, and far from attempting to maintain old friendships, AWLD deny being part of this group, going as far as to choose non-disabled partners. The self-advocacy movement is going some way to redress this denial and towards the celebration of difference.

However, AWLD want friends and all of the benefits that friendship can offer, including company, increased self-esteem, intimacy and a sense of self identity, whatever way this is derived (Richarson and Ritchie 1989). It is clear that groups were separated geographically during deinstitutionalisation (or devalued these friendships once in the community) and could remain socially distanced from non-disabled people by their experience of stigma.

To be cared about, not for, is the key issue within friendships and inherent is the idea of reciprocity. As seen in the typologies of social support and staff interaction styles, the opportunity to "give and take" is not apparent for AWLD and is highlighted as a recommendation for improvement in the "Twelve Years On" study (Forrester-Jones et al 2001).

CONCLUSION

It can be seen that social networks for AWLD is a contentious issue, where access to social contacts to form networks, beneficial effects and maintenance of benefits such as friendships are subject to complex interactions of a number of mediators.

Service systems both within services (the home) and the community, family, policy, value-based agendas, their own psychological self-concept, and additional difficulties all impact upon the dimensions of an individual's social network at a structural and functional level. New service systems that seem to offer more beneficial social network outcomes, such as supported living and employment, require closer research and time to fully attempt to achieve the full benefits for all people, as do policy and policy statements, such as the White Paper "Valuing People" (DoH 2001), which highlighted the challenge to services of helping people to sustain relationships.

This report included intimate and physical relationships, noticeable by their absence in the research and literature in any measure. Ageing is also an emergent area of research, both universal and pathological.

REFERENCES

Atkinson, D (1989) How easy is it to form friendships after leaving long stay hospitals? Social Work Today, 18, 41, 12-13

Barnes, J (1954) Class and committees in a Norwegian island parish, Human Relations, 7, 39-58

Bass, M & Drewitt, R (1997) Real Work: Supported Employment for People with Learning Difficulties, Sheffield: Joint Unit for Social Services Research, University of Sheffield

Benzeval, M; Judge, K & Whitehead, M (1995) (eds) Tackling Inequalities in Health: An Agenda for Action, London: Kings Fund Centre

Beyer, S (1996) Real jobs and supported employment. In Philpot, T & Wards, L (eds) Values and Visions: Changing Ideas in Services for People with Learning Difficulties, London: Butterworth Heinemann

Blaxter, M (1990) Health and Lifestyles, London: Tavistock/Routledge

Booth, T; Simons, K & Booth, W (1990) Outward Bound: Relocation and Community Care for People with Learning Difficulties, Milton Keynes: Open University Press

Brown, G.W & Harris, T (1978) Social Origins of Depression, London: Tavistock

Cambridge, P; Carpenter, J; Beecham, J; Hallam, A; Knapp, M; Forrester-Jones, R & Tate, A (2002) Twelve years on: The long term outcomes and costs of deinstitutionalisation and community care for people with learning disabilities, Tizard Learning Disability Review, 7, 34-42

de Kock, U; Saxby, H; Thomas, M & Felce, D (1988) Community and family contact: An evaluation of small community homes for severely and profoundly mentally handicapped adults, Mental Handicap Research, 1, 127-140

DoH (1989) Caring For People, London: Department of Health

DoH (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century, London: Department of Health

Emerson, E; Hatton, C; Felce, D & Murphy, G (2001) Learning Disabilities: The Fundamental Facts, London: Mental Health Foundation

Fehr, B (1996) Friendship Processes, London: Sage

Fisher, C.S (1982) To Dwell Amongst Friends, Chicago: University of Chicago Press

Forrester-Jones, R.V.E (2001) Friendships and social integration through leisure, Tizard Learning Disability Review, 6, 28-32

Forrester-Jones, R.V.E (2002a) Relationships in the lives of people with learning disabilities: The Elfreida lectures 1997/1998, Tizard Learning Disability Review, 7, no.4

Forrester-Jones, R.V.E (2002b) Lecture Notes from MSc in Analysis and Intervention with Adults with Learning Disabilities, Canterbury: Tizard Centre, University of Kent

Forrester-Jones, R.V.E & Grant, G (1997) Resettlement from Large Psychiatric Hospitals to Small Community Residences, Aldershot: Avesbury

Forrester-Jones, R.V.E; Carpenter, J; Coolen-Schrijner, P; Cambridge, P; Tate, A; Beecham, J; Hallam, A; Knapp, M & Woolf, D (2001) The social networks of people living in the community twelve years after resettlement from long-stay hospitals. In Cambridge, P et al (eds) Twelve Years On: Outcomes and Costs of Community Care for People with Learning Disabilities and Mental
Health Problems, Canterbury: Tizard Centre, University of Kent

Gottlieb, B.H (1978) The development and application of a classification scheme of informal helping behaviours, Canadian Journal of Behavioural Science, 10, 105-115

Grant, G (1993) Social networks and transitions over two years among adults with a mental handicap, Mental Handicap Research, 6, no.3

Hammer, J (1980) Social access and the clustering of personal connections, Social Networks, 2, 305-325

Holland, A & Meddis, R (1997) People living in community hones: Their views, British Journal of Learning Disabilities, 25, 68-72

Kings Fund (1980) An Ordinary Life: Comprehensive Local Based Residential Services for Mentally Handicapped People, London: Kings Fund Centre

Kings Fund (1984) An Ordinary Working Life: Vocational Services for People with a Mental Handicap, London: Kings Fund Centre

Kinsella, P (1992) Supported Living - A New Paradigm, National Development Team

Krauss, M.W & Erickson, M (1998) Informal support networks amongst ageing persons with mental retardation: A pilot study, Mental Retardation, 26, 4, 197-201

Mank, D; Cioffi, A & Yovanoff, P (1997) Employment outcomes for people with severe disabilities: Opportunities for improvement, Mental Retardation, 36, no.3

McConkey, R & McGinley, P (1990) A time to be free. In McConkey, R & McGinley, P (eds) Innovations in Leisure and Recreation for People with a Mental Handicap, Chorley, Lancs: Liseaux Hall

Melling, K (1997) Supported employment in Britain, Tizard Learning Disability Review, 2, no.2

Milardo, M (1992) Comparative methods for delineating social networks, Journal of Social and Personal Relationships, 9, 447-461

Myers, F; Agers, A; Kerr, P & Myles, S (1998) Outside looking in? Studies of the community integration of people with learning disabilities, Disability and Society, 13, no.3

Newton, S; Olson, D & Homer, R (1995) Factors contributing to the stability of social relationships between individuals with mental retardation and other community members, Mental Retardation, 33, 6, 383-393

Oullette, L; Horner, R.H & Newton, J.S (1994) Changing activity patterns to improve social networks: A descriptive analysis, Behavioural Intentions, 9, 1, 55-66

Pahl, J & Quine, L (1985) Examining the causes of stress in families with severely handicapped children, British Journal of Social Work, 15, 501-517

Rapley, M & Beyer, S (1996) Daily life, community participation and quality of life in an ordinary housing network, Journal of Applied Research in Intellectual Disabilities, 9, 31-39

Richardson, A & Ritchie, J (1989) Developing Friendships, London: Policy Studies Institute

Simons, K & Watson, D (1999) New Directions? Day Services for People with Learning Disabilities in the 1990s A Review of the Research, Bristol: Norah Fry Research Centre, University of Bristol

Smith, P & McCarthy, G (1996) The development of a semi-structured interview to investigate the attachment-related experiences of adults with learning disabilities, British Journal of Learning Disabilities, 24, 154-160

Srivastava, A (2001) Friendships and social integration through leisure for people with moderate, severe and profound learning disabilities transferred from hospital care, Tizard Learning Disability Review, 6, 19-27

Szivos, S (1991) Consciousness-raising: An attempt to redress the more repressive aspects of normalisation, but not it's more positive ones, Clinical Psychology Forum, June, 28-31

Szivos, S (1992) The limits to integration? In Brown, H & Smith, H (eds) Normalisation: A Reader for the Nineties, London: Routledge

Szivos-Bach, S.E (1993) Social comparisons, stigma and mainstreaming: The self esteem of young adults with a mild mental handicap, Mental Handicap Research, 6, no.3

Wall, K (1998) Friendship Skills and Opportunities among People with Learning Disabilities, Norwich: Department of Social Work, University of East Anglia

Wertheimer, A (1996) (ed) Changing Days, London: Kings Fund

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